Practice Improvement Protocol 4

SPECIAL CONSIDERATIONS FOR ASSESSMENT AND TREATMENT OF BEHAVIORAL HEALTH DISORDERS IN INDIVIDUALS WHO HAVE DEVELOPMENTAL DISABILITIES

Developed by the
Arizona Department of Health Services
Division of Behavioral Health Services

Effective April 6,1999
Last Revised April 3, 2003

Purpose: This practice Improvement protocol is designed to assist clinicians in providing quality assessments and treatment services for individuals with behavioral health conditions associated with developmental disabilities.

I. Service Population

Diagnosis:[1] Autism, Childhood Disintegrative Disorder, Rett's Disorder, Pervasive Developmental Disorder, Pervasive Developmental Disorder, Not Otherwise Specified, Asperger's Disorder, Mental Retardation (intellectual disability), Down's Syndrome, Fragile X Syndrome, Fetal Alcohol Syndrome and other peri-natal substance exposures, Head injury or seizure disorder prior to age 18 with loss of cognitive function and impairment in one or more domains of functioning, other syndromes with prominent intellectual disability; cerebral palsy.

II. Desired Outcome:

A. Change in Target Signs and Symptoms:

1. Observable improvement in prominent psychiatric symptoms of the identified disorder.

2. Decreased dysfunctional behaviors attributable to the psychiatric disorder (or behaviors attributable to the developmental disability that respond to behavioral health intervention).

B. Functional Improvement

The individual will be able to maintain behavior appropriate to his/her cognitive/developmental level in multiple settings, including home, school,

[1]Although all of these diagnoses are "developmental disabilities," the only diagnoses that are currently eligible for services from DDD are cerebral palsy, epilepsy, mental retardation and autism, with significant functional limitations in at least three domains of daily living that are directly attributable to the developmental disorder.

work or social settings.

C. Environmental Support:

1. Family, other primary social supports and caregivers will have learned to respond appropriately to signs and symptoms of the disorder (including self-report of the individual), and will have learned to identify warning signs of recurrence of the disorder.

2. The family and/or other caregivers will have learned to promote positive interactions and to moderate the family's response to conflict.

III. Co-Morbid Conditions:

Compared to the general population, individuals with developmental disorders are more likely to experience a variety of behavioral health disorders.

IV. Recommended Practice and Coordination:

A. Behavioral Health Services:

1. Individuals with developmental disabilities are more susceptible to behavioral health disorders than the general population, and so should be examined with a high index of suspicion.

2. It should not be assumed that the presence of developmental disabilities automatically precludes the individual's participation in goal setting or treatment planning, or would render any particular treatment modality ineffectual. Individuals must be assessed in light of their unique strengths and limitations and their potential to participate and progress in all aspects of their care. Communication should always be geared to the individual's level of comprehension.

3. If indicated by the psychiatrist or primary behavioral health professional, evaluations should be conducted by primary care, endocrinology, neurology, psychology, and other specialty services as applicable.

4. All available and requested assessment historical information should be reviewed and integrated into an understanding of the individual in the context of his/her present environmental context. Family members, care givers, and when appropriate, members of the child/family team should be included to the extent possible in all aspects of the assessment process and ongoing care.

5. In performing initial and ongoing behavioral health assessments, the clinician should be aware that symptoms are frequently not reported by individuals with developmental disorders, and so the clinician may need to rely on externalized behaviors, behavioral and vegetative changes, and the availability of an adequate reporter at the time of the visit.

6. Psychiatric assessments and management for individuals under 13 years of age should be performed by or in consultation with child and adolescent psychiatrists.

7. In collaboration with the family, caregivers, other primary social supports and other involved professionals; a list of targeted symptoms and treatment goals should be developed. The frequency and severity of target signs and symptoms should be documented at the initiation of therapy. Changes in frequency and severity of target signs and symptoms should be documented as therapy progresses. The child/family team should agree upon realistic goals and a realistic pace for change.

8. Psychopharmacological interventions

    i. To rule out environmental causes of symptoms, the individual should demonstrate the targeted syndrome in at least two out of three settings before a psychopharmacological trial is considered.

    ii. In general, basic treatments for these conditions do not differ from that of the general population. If a general psychiatric

condition is identified, the appropriate pharmacological approach for that condition should be employed, without regard to the developmental disorder. It is important to consider that individuals with developmental disabilities are generally more sensitive to medications and more likely to experience side effects. Starting psychotropic medications with low dosages and adjusting/increasing dosages slowly is commonly recommended.

iii. The use of multiple medications should be evaluated carefully because of their synergistic effect in raising or lowering expected blood levels. Because of possible drug interactions between and among prescription medications, over-the-counter medications, non-traditional healing substances, herbs, and even foods such as grapefruit juice; all substances taken and dietary practices should be documented and evaluated.

iv. For those individuals with developmental disorders who do not have a separate identified psychiatric condition, but primarily have behavioral symptoms associated with their developmental disorder, treatment should be symptomatic, using a thoughtful rationale to select an initial drug trial based on the observed behavioral syndrome.

9. Cognitive-behavioral strategies may be used, with increased weight on the behavioral component for lower functioning individuals. Caregivers, family members and other providers in the individual's environment should be actively engaged, including involvement with "homework" assignments. Strategies must be integrated with other services, and must be based on a thorough familiarity of the individual's environment, routine, strengths and limitations and the assured cooperation of the individual's caretakers, guardians, educators and other staff. As for all other service strategies, signs/symptoms of relapse or recurrence and exacerbating factors for the co-occurring behavioral health disorder should be identified and strategies developed for coping with exacerbating factors.

Achievable and relevant goals and objectives should be identified, and realistic expectations of progress established, as chaining and generalization of goals may occur slowly.

10. For changes in life circumstances and other stresses that lead to emotional or behavioral disturbances, brief supportive treatments should be employed, as for any other individual, by clinicians who are competent to perform psychotherapeutic interventions geared to the developmental level of the individual.

11. Early Identification of Individuals with Developmental Disorders -]

    Children do best when behavioral health needs are identified and treated early. Treatment should be initiated at the first indication of behavioral compromise in order to limit the development of more severe symptoms.

12. Service provision should be built on the Arizona Principles and should rest, to the extent possible, on connections to natural supports; community based services and respect for the individual's unique cultural heritage and needs.

B. Medical Health Services:

1. The psychiatrist, primary behavioral health professional or assigned clinician must ensure that there is collaboration among medical providers, including psychiatric, psychological, pediatric, neurological and endocrinological specialists.

2. All relevant information, including the initial assessment and treatment plan, must be communicated to the primary care physician, and behavioral health and medical services must be coordinated.

3. As with behavioral health services, medical services are most effective when implemented as early as possible. Efforts to help a child learn and use language by age 8 are essential. These services should include a combination of behavioral and language based

interventions, such as speech therapy, occupational therapy, one to one behavioral-language therapy (Applied Behavioral Analysis Techniques), sensory communication boards or picture boards, and evaluations for oral apraxias, expressive and receptive language abilities and hearing. Care and consultation between specialists should be coordinated with the client's Primary Care Provider (PCP).

C. Collateral Resources/Ancillary Services:

1. Protection & Advocacy:

While remaining aware of the incidence of self-injurious behavior in this population, reports to Child/Adult Protective Services (CPS or APS) must be made when there is suspicion of neglect or abuse, including medical or emotional. For open CPS or APS cases, the protective services case plan must be coordinated with the behavioral health services. CPS case managers must be invited to all behavioral health services staffings and reviews.

2. Division of Developmental Disabilities:

If the individual is not yet enrolled in DDD, and mental retardation, autism, or a qualifying seizure disorder is diagnosed, referral to DDD should be made for eligibility determination. If DDD is providing services related to the developmental disability, such services must be coordinated with the behavioral health services. DDD support coordinators must be invited to all behavioral health services staffings and reviews. All relevant information, including the initial assessments and treatment plan, must be communicated to DDD to ensure coordination of services. Per the ADHS/DES/DDD IGA and Operational Procedure Manual, for DDD/ALTCS individuals, the DDD support coordinator is the lead case manager.

3. Probation, Parole, Correctional Facility, or Other Civil/Criminal Court:

If court, probation and parole officers are involved with the individual, conditions of probation, parole and related services should be coordinated with the behavioral health services.

4. AHCCCS/ALTCS:

Individuals with physical disabilities that require long-term care should be referred to ALTCS for eligibility determination. If ALTCS is providing services, such services should be coordinated with the behavioral health services.

5. Education:

The parent/legal guardian will be advised to request the school district's cooperation. This will include the school's participation in the initial and ongoing evaluation and interventions. The parent may also request the school to provide a comprehensive educational evaluation to determine the need for additional support services such as occupational, physical, or speech therapy, special education eligibility, IQ testing, or an accommodation assessment. The behavioral health professional should participate in the development of the Individual Education Plan (IEP) to assist the school in maintaining the individual in the least restrictive individual educational setting.

6. Vocational Rehabilitation:

Vocational training may be available through the school to individuals who are under the age of 16 and designated as emotionally handicapped (EH). For persons 16 and over, referral to VR services should be considered and services coordinated, if appropriate.

VII. Medication Practices

Because of concomitant seizures, metabolic disorders and other medical problems, individuals with developmental disorders have an increased likelihood of drug/drug interactions, side effects, and psychiatric, physical or behavioral symptoms caused

by complex pharmacological regimens. Therefore, a comprehensive medical/psychiatric approach, as described below, is necessary for optimal treatment.

A. Prior to initiating pharmacotherapy, the clinician should:

1. Assure that the individual and guardian understand the treatment, risks and benefits, and can report appropriately (consent by silence and passive acceptance cannot be assumed);

2. Document baseline functioning, including a baseline Abnormal Involuntary Movement Scale (AIMS), appropriate laboratory studies, vital signs, height and weight, activity and sleep pattern;

3. Understand any limitations of the environment, including the use of PRN medications;

4. Identify observable, measurable symptoms to be followed and clarify the monitoring and reporting of these symptoms with the individual's family, home staff, case managers/support coordinators and/or guardian.

B. At follow-up visits the clinician should:

1. Follow vital signs, weight, and lab values closely;
2. Recheck serum medication levels as appropriate;
3. For anti-psychotic medication, repeat and document AIMS testing at least every six months;
4. Monitor the capacity of the environment to support the recommended treatment plan;
5. Monitor progress, or lack thereof, and adjust treatment accordingly.

VIII. Special Assessment for Eligibility for Developmental Disabilities Services

A. The Division of Developmental Disabilities provides support and habilitative services for individuals with significant functional limitations due to:

1. Cerebral palsy
2. Epilepsy
3. Mental retardation
4. Autism

Diagnosis is necessary but not sufficient for DDD eligibility; the individual must also have significant functional limitations in at least three domains of activities of daily living, which are directly attributable to the developmental disorder (see Section C below).

B. Information Needed Prior to DDD Application

When an individual with a developmental disability who is not enrolled with DDD presents to the behavioral health provider, the provider should first call the DDD district office or central office to verify DDD enrollment eligibility status. If the individual has not previously been reviewed for eligibility and is not currently enrolled with DDD, the qualifying diagnosis must be documented before initiating a referral. It is the responsibility of the applicant to acquire and provide the appropriate documentation for DDD eligibility. The Division does not provide individual psychiatric or psychological assessment services:

1. If eligibility is based on cognitive limitation:

   i. The individual must demonstrate a diagnosis of mental retardation as determined by a qualified psychologist using a standardized, culturally appropriate instrument (e.g. Vineland, Bailey, WISC-R, WRAT, CARS, ADI). The schools may provide these assessments when appropriate.

   ii. The cognitive limitation cannot be associated with a delirium due to general medical or psychiatric illness, or pharmacological intervention.

   iii. The cognitive limitation cannot be primarily due to a learning disability or language processing disorder.

2. If eligibility is based on the presence of autism:

   i. The individual must have written documentation of the clinical evaluation and diagnosis by an appropriately trained physician.

   ii. The individual must have significant functional limitations in at least three areas or spheres of daily living directly attributable to the developmental disorder and not due to other medical or psychiatric conditions (see C below).

C. Spheres of Daily Living/Domains of Functioning:

These are the areas that are evaluated by DDD to determine the presence of significant functional limitations:

1. Self-Care
2. Receptive and Expressive Language
3. Learning
4. Mobility
5. Self-Direction
6. Capacity for Independent Living
7. Economic Self-Sufficiency

D. Determination of Eligibility

If the above conditions have been satisfied, the individual should be referred to a DDD Intake Office for a formal review of eligibility. A referral should also be made to AHCCCS to determine ALTCS eligibility.

Eligibility is determined by the support coordinator supervisor in rural areas, and by specialized intake workers in Maricopa and Pima County. Intake workers must have at least a bachelor's degree with work experience in developmental disabilities. Intake workers have access to a psychologist and psychiatrist for review of questionable cases.

E. Time Frames for Determination of DDD Eligibility

If the DDD application is initiated through the ALTCS office, a determination must be made within 30 days of the application; if an individual and family apply through DDD, a determination must be made within 60 days of application.

F. ALTCS vs. non-ALTCS

If individuals are DDD-ALTCS, they are entitled to all Title XIX covered services. If individuals are eligible for DDD, but are not DDD-ALTCS or Title XIX eligible, services are provided based on availability and funding. The DDD non-ALTCS, Non-Title XIX individual may be placed on a waiting list if needed services or funds are not available.